

# **The Caregiver**

## **Newsletter of the Duke Family Support Program**

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Joseph and Kathleen Bryan  
Alzheimer's Disease Research Center

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### NORTH CAROLINA ALZHEIMER'S ASSOCIATION NEWS

**Eastern NC Alzheimer's Association** – Memory Walk and 5K Run October 2<sup>nd</sup> at Fayetteville St. Mall; Caregiver Education Conferences in Henderson on October 14<sup>th</sup>, Raleigh on October 27<sup>th</sup>, Lumberton on November 16<sup>th</sup> and Greenville on December 9<sup>th</sup>. Check [www.alznc.org](http://www.alznc.org) for more info.

**Western Carolina Alzheimer's Association:** Free family education events in Charlotte, Monroe, Peachland, Greensboro, Morganton, Hickory and High Point. Early stage memory loss support group in Charlotte. Annual Caregiver Education Conference November 4<sup>th</sup> in Black Mountain and Special Program on Treatment and Prevention Trials at Discovery Place in Charlotte November 9<sup>th</sup> featuring Duke's Dr. Murali Doraiswamy. Candlelight Reflections tribute to families affected by Alzheimer's in Winston Salem on November 9<sup>th</sup> and Greensboro on November 16<sup>th</sup>. See website listed above for more information.

# Altruism Meets Alzheimer's

By Katy Lowry, Duke Family Support Program  
Gabel Leadership in an Aging Society Intern, 2004  
Duke University Class of 2005

Bob and Elsie Jones (whose names have been changed for privacy) both grew up on family farms in North Carolina. He was two years ahead of Andy Griffith in Mount Airy, and she grew up nearby. Both agree that their upbringing instilled in them the importance of helping others. So when Elsie was diagnosed with Alzheimer's disease (AD) in 2003 at Duke's Bryan Alzheimer's Disease Research Center, they were eager to find ways to help future generations by contributing to research.

Their son, Tom, approached Dr. Schmechel, a neurologist at Duke and Director of the Bryan ADRC, about their family's strong history of Alzheimer's disease. When Tom told Dr. Schmechel that out of Elsie's nine siblings, at least five had developed late-onset Alzheimer's disease, Dr. Schmechel encouraged their family to donate blood samples to the National Cell Repository for Alzheimer's Disease (NCRAD) at Indiana University. This repository is part of a major new initiative sponsored by the National Institute on Aging (NIA) to accelerate the pace of AD genetics research. As part of this initiative, blood samples from over 1,000 families will be collected. The NIA's AD Genetics Initiative encourages data sharing by making the repository available to researchers around the world so more studies can be run simultaneously with the same data. The initiative began as a direct recommendation from leading AD genetic researchers (including Duke's Dr. Donald E. Schmechel) in 2002. They recognized an urgent need to accelerate the pace of discovery of genes that may contribute to or protect one from the development of late-onset Alzheimer's disease. "Unless we do this, we have no chance of understanding this disease," Dr. Schmechel says. "There

are still about 5-7 genes that are out there waiting to be discovered that could give us new treatment ideas."

Marcelle Morrison-Bogorad, Ph.D., Associate Director of the NIA for the Neuroscience and Neuropsychology of Aging Program, explains that the discovery of these genes will have clinical implications. "Discovery of risk factor

genes will help . . . identify new targets for drug therapy. Those who carry these risk factor genes would be high priority participants in Alzheimer prevention

trials," she says. "We need to reduce the time it takes to do these studies, cut the costs involved, and find ways to conduct effective studies with fewer numbers of participants. Addressing these challenges is an increasingly important part of the national Alzheimer's research agenda," she adds.

In order to identify these genes, researchers must find families with a sibling pair (brother/sister) over the age of 60, both of whom have diagnoses of probable

*"Unless we do this, we have no chance of understanding this disease."*

**Dr. Donald Schmechel,  
Bryan ADRC Director**

## Who Can Help?

**NCRAD researchers are looking for families with at least 3 members who can donate blood, including:**

- Two siblings who developed late-onset AD after the age of 60, AND
- Another family member over the age of 50 who may have memory loss OR a family member over the age of 60 who does not have memory loss

Alzheimer's disease and at least one other family member who may or may not have Alzheimer's disease. Because each person has approximately 30,000 genes, family units offer the most valuable information in genetics research because siblings share approximately 50% of the same genetic information. Using this information, researchers believe it is possible to ultimately identify the additional genes involved in the development of the most common form of late-onset AD. Many genetic studies also examine the DNA of controls, often spouses of the person with Alzheimer's, like Mr. Jones. The identification of these genes will help explain the mechanism and the biology of the disease, leading to prevention, delay and treatments. It may also point to certain environmental factors such as diet that may be linked to the development of the disease.

Alzheimer's Disease Research Centers nationwide are contributing to this initiative, including the Bryan Alzheimer's Disease Research Center at Duke University. Collaborating with the Bryan ADRC on this effort, Duke University Center for Human Genetics (CHG) is jointly recruiting for its Alzheimer's disease genetics studies and for

NCRAD. Patients and families who choose to participate in a Bryan ADRC-CHG study may opt to have a portion of their blood sample and information sent to the repository at Indiana University. This option enables participating families to assist in multiple studies with only a single blood collection. Dr. Schmechel proposes the idea to every patient seen in the clinic who may be eligible for participation. Many of his patients are pleased to have the opportunity to be involved. "Dealing with Alzheimer's disease is difficult, and patients who are having a hard time often see it as a positive step they can take," Dr. Schmechel says.

Dr. Schmechel encouraged Tom to be the liaison to his family and identify family members who could be eligible to participate, and he encouraged Tom to discuss the possibility of participation with them. Tom identified 29 family members from Elsie's living siblings and their children. All six of Elsie's living siblings agreed to participate.

"I believed I would get a good response because my cousins had already asked me if there was anything they could do. They wanted to help their children and their children's children," Tom says.

Pete Gaskell, physician assistant and Alzheimer's disease study coordinator at the CHG, discussed the details of the study with Mr. And Mrs. Jones while they were in the clinic to see Dr. Schmechel. He and their son worked together to arrange home visits to collect blood from the family members who wished to participate. Gaskell emphasizes that participation in a genetics study is a family decision, and the Bryan ADRC-CHG treats it as such. One of the tricky issues associated with recruitment for Alzheimer's family studies is assessing the extent to which the person with Alzheimer's disease understands his or her participation. To address this issue, study coordinators must obtain both *assent*

#### **Facts About Participating in NCRAD:**

- **Participants will be asked to give a blood sample, complete a telephone or in-person interview, and have a medical exam with memory testing (if needed)**
- **All information is kept confidential**
- **Participants can live anywhere in the U.S., and family members do not have to live near each other**
- **Participation is voluntary**
- **There is no cost to participants**
- **Participation does not affect your health care**



from the patient and *consent* from the family. Gaskell works with the person with AD to provide them with a general understanding of the study that makes sense to him/her in order to assure *assent*, or general willingness, to participate. However, the person cannot be enrolled in any study without the official *consent* of the primary family caregiver or an immediate next-of-kin who demonstrates full understanding of the study.

It is not uncommon for families to have questions and concerns when considering whether or not to participate in genetics research. As a study coordinator, Gaskell attempts to allay some of these concerns. "Some people fear that by participating, they will find out whether or not they will get Alzheimer's. We emphasize that no

information about an individual's genetic testing will be disclosed to him or her," Gaskell says. "Another concern expressed by families is fear about the confidentiality of the testing and how the results may affect their health insurance. Again, we go to great lengths to explain to these research volunteers that confidentiality of their results is as critical to research as it is to them. Under no circumstances do we release their names, nor their genetic information, nor any other information to *anyone*, including insurance companies, physicians, or even other family members." Gaskell also emphasizes that all genetic information sent to Indiana University for NCRAD is sent anonymously, so the combined national data set will not contain participants' names at all.

What do these families have to gain from their participation? According to Gaskell, "Participation in genetic research is total altruism. The results of the genetic testing cannot even be disclosed to [the

participants.] We can only hope that it will help the next generation, or the one after that." Gaskell emphasizes that it will not be the efforts of any individual family that will answer Alzheimer's genetic questions, but rather it will be the efforts of large families joining together. "It's a public health issue," Gaskell claims.

But from his experience, Gaskell believes that participating families find it rewarding to contribute to AD research. Given that participation is not invasive or extremely time consuming, it is a relatively simple way to play an active role in the nationwide effort to develop new treatments for the disease. "It is one way for people to feel that, in spite of what is happening to them, they can give something to help others who might be at risk for the same experience."

The Jones family agrees. "If it might help somebody else, we're willing to do it," they say.

Participating families also receive regular newsletters through their Alzheimer's Disease Research Center physicians. These national newsletters provide up-to-the-minute reports on research progress. As of August 2004, 632 families have enrolled nationally for the study, more than half of the goal of 1000 families.

*"It is one way for people to feel that, in spite of what is happening to them, they can give something to help others who might be at risk for the same experience."*

**Pete Gaskell,  
CHG Study Coordinator  
for AD research**

**Anyone interested in participating in NCRAD through the Bryan ADRC-Duke CHG or other Bryan ADRC/CHG research should contact Ron Nelson toll free at 1-866-444-2372 or Pete Gaskell toll free at 1-866-385-2591. Studies at the Bryan ADRC/CHG are recruiting anyone with a diagnosis of probable AD.**

**ADVANCES IN RESEARCH**(from The Duke Aging *Center Report* – Summer 2004)**Cardio- and Cerebrovascular Risk Factors for Alzheimer's Disease**

By Kathleen Hayden, PhD

Post Doctoral Fellow, Duke Center for Aging

Cardiovascular risk factors have long been associated with vascular dementia (VaD). These factors are now being implicated in mild cognitive impairment as well as Alzheimer's disease (AD). Hofman et al., found a significant relationship between levels of atherosclerosis and AD in a population-based study of over 1,900 people. While the estimates of effect were significant, the study was a cross-sectional evaluation. These findings spurred interest in the association between atherosclerosis and AD and researchers are now linking risk factors such as midlife blood pressure levels, cholesterol levels, and diabetes to later development of AD.

**High Blood Pressure:**

Hypertension has received a great deal of recent attention as a leading cardiovascular risk factor for AD. A number of epidemiologic studies have identified variations in blood pressure levels in Alzheimer's disease, before and after onset of the disease. Evidence from these studies indicates that the risk of all forms of dementia is associated with elevated blood pressure at midlife. One of the first studies to examine the link between hypertension and AD found that long-term hypertension was associated with AD pathology. Hypertension can cause damage to blood vessels over time and may lead to thickening of vessel walls which can result in the development of white matter lesions in the brain. These lesions are micro-vascular changes and have been found in the brains of patients with AD.

**High Cholesterol:**

High cholesterol is another leading cardiovascular risk factor that has been implicated in risk of AD. It is associated with vascular disorders (including atherosclerosis) which may confer an increased risk for AD. Several population-based, longitudinal studies have indicated that, similar to hypertension, elevated cholesterol at midlife is associated with later onset of AD. However, some studies failed to find any such relationship between cholesterol levels and later AD onset.

**Diabetes:**

The potential relationship between diabetes and AD has been studied for some time. Researchers have suggested that abnormal glucose metabolism in the brain may predate the onset of AD by as much as two or three decades. It has been hypothesized that the damage to the blood vessels caused by diabetes may precipitate AD. Recent reports have implied connections in the mechanisms behind type 2 diabetes and AD, and in common genetic predispositions for both insulin resistance and AD.

Several longitudinal population-based studies have investigated the association between diabetes and AD. Two of these studies found an increased risk for AD in males with diabetes. In one study, the risk for females was elevated, but was not statistically significant. Another study evaluated the association according to type of treatment (i.e., diet, pills, or insulin) and showed a significant elevated risk of AD in those receiving insulin treatments.

**Stroke:**

The consequences of stroke have long been associated with vascular dementia (VaD) or so-called multi-infarct dementia. However, in recent years stroke has been investigated as a

precipitating event for AD. Most notably, an association between stroke and cognitive function was found in a study of Catholic nuns<sup>2</sup>. More severe cognitive deficits were found in nuns who had suffered a stroke. Among nuns who met neuropathologic criteria for AD, those who had suffered a stroke had significantly lower scores on the Mini Mental State Exam.

More recently, Honig et al. reported an increased risk of AD in study participants with a history of stroke in a population-based cohort (n=1766) of persons age 65+ in upper Manhattan<sup>3</sup>. We found similar results in a cohort study of individuals (n=3167) aged 65 or older in Cache County, Utah, although they were not statistically significant<sup>4</sup>.

There is a growing consensus among researchers that vascular dementia subtypes and Alzheimer's disease may rarely present as separate conditions. There are a multitude of pathways whereby cardiovascular health can influence AD risk. Due to the nature of the diagnostic criteria for AD, the link between cardiovascular risk factors, cerebrovascular disease, and AD has been difficult to evaluate. The mounting evidence of an association between cardiovascular health and AD may help to identify means by which people can prevent or delay the onset of this devastating disease. At the very least, it should encourage people to take measures to improve their cardiovascular health.

1. Hofman, A. et al. Atherosclerosis, apolipoprotein E, and prevalence of dementia and Alzheimer's disease in Rotterdam Study. *Lancet*, 1997. 349-(9046):p. 151-4.
2. Snowdon, D.A. et al., Brain infarction and the clinical expression of Alzheimer's disease. The Nun Study. *JAMA*, 1997. 277(10):p. 813-7.
3. Honig, L.S., et al., Stroke and the Risk of Alzheimer's Disease. *Arch Neurol*, 2003. 60(12): p. 1707-1712.
4. Hayden, K.M., Pieper, C.F., Welsh-Bohmer, K.A., Breitner, J.C.S., Norton, M.C. & Munger, R. for the Cache County Investigators. Stroke and the risk of Alzheimer's disease. *Arch Neurol*, 2004. 61:982

**The Nineteenth Annual Joseph and Kathleen Bryan  
Alzheimer's Disease Research Center Conference**

**Alzheimer's 2005**

**Thursday and Friday  
February 10-11, 2005**

**Durham Marriott at the Civic Center  
201 Foster Street  
Durham, NC**

See <http://adrc.mc.duke.edu>  
for brochure and registration  
details, or call the Bryan ADRC  
Education Core – toll free in NC  
800-672-4213 or 919-660-7510.

## *Husbands Tune-In to Wives' Worlds*

By Katy Lowry, Duke Family Support Program  
Gabel Leadership in an Aging Society Intern, 2004

*From Durham, North Carolina-*

When his wife experienced a personality change about fifteen years ago, Bob Gordon says he never considered Alzheimer's disease the culprit. "I know now that she suspected it long before I ever knew," he says. Marge started donating to Alzheimer's Disease International without her family's knowledge in the mid 1990's. Her memory problems eventually led her to voluntarily give up driving. Only after many years was she diagnosed with Alzheimer's Disease at the Duke Geriatric Evaluation and Treatment Clinic in November 1998.

Bob cared for Marge at home for many years until he felt unable to provide her the level of care she needed. Like all caregivers confronted with caring for a relative with Alzheimer's, Bob faced many challenges unlike any he had encountered before. While he was able to find information about some of the basic tasks of caregiving, Bob became frustrated that there was so little available information about some of the logistics of later-stage care. For example, Marge had difficulty keeping her balance while walking, making falls a constant concern. Also, as Marge's weight fluctuated, Bob struggled to find the right sizes for clothing, bras, and underwear. He also worried that he would not recognize a medical problem when it appeared because he was unable to find information about appropriate timing for urination and bowel movements.

*"Tune into their wavelengths. They broadcast what they want."*

As an engineer by trade, Bob was accustomed to approaching all challenges from a problem-solving perspective. Using this approach, Bob identified many solutions to these everyday problems. For example, he realized that Marge's balance improved when she did not try to consciously control it. By walking backwards and facing her while she walked, he was able to distract her so that her walking improved and she fell less frequently. Creating routines and adhering to them also minimized mechanical challenges such as dressing, bathing, and eating.

But Bob says the most important aspect of caring for Marge at home was his awareness of her mood, interest, and disinterest. "Tune into their wavelengths. They broadcast what they want," Bob advises.

### **Bob's Care Tips for Later-Stages**

- Use liquid bandage for injuries instead of band-aids
- If she falls, distract her – "hovering" is only alarming
- Use body pillows to prevent falling out of bed
- Make sure shoes fit well and are very supportive to aid walking
- Interact one-on-one, it's easier for her to focus
- Old movies and musicals are great entertainment – avoid TV shows with commercials
- News channels can be distressing
- Read aloud quietly at a 5<sup>th</sup>/6<sup>th</sup> grade level
- Keep noise to a minimum
- Always approach from the front

Bob says he learned he could not force activities on Marge. When she first started developing symptoms, Bob attempted to help her remember people and places with old photo albums and scrapbooks, including one scrapbook that Marge made when she first realized that she had the disease. During the later stages, however, he realized that the albums were no longer helpful. Instead, they became embarrassing for her and frustrating for him. "To her, it was like I was telling her that she was going downhill. That's very alarming," he says.

*"You can't decide for them what they want to do. Accepting that fact is really important."*

When Bob let Marge set the pace and tone of their day-to-day activities, she was more content.

If she wanted to go somewhere, they went together. They sang together, but he knew that as soon as Marge stopped singing, it was his cue to stop as well. If he read to her and she

became distracted, he knew to stop reading. If she wanted to hold hands, they held hands. But if she withdrew, he knew that he could not force it on her. "If she became agitated or disinterested, I just had to stop. You can't decide for them what they want to do. Accepting that fact is really important."

### *From Kingwood, Texas-*

Stephen Unwin, a husband caregiver from Texas via the UK, also found this approach helpful. Mr. Unwin compares Alzheimer's disease to a computer malfunction. "The Alzheimer's sufferer tries to reboot, but is only frustrated when they click the button and nothing happens. You know the feeling. It makes you mad," he says. "So the carer must adapt and adjust as well as the sufferer."

Mr. Unwin describes how his adjustment included going for six hour drives, listening to Lawrence Welk, getting up in the middle of the night to watch worship videos, and going to McDonald's at the crack of dawn everyday. It may mean letting her wander throughout the house opening and closing closet doors, as long as the front door is locked. It may mean planting the yard, eating gallons of ice cream, and moving back the furniture to let his wife roll on the floor. "It's good exercise and there's no harm in that," he explains.

*"Human beings need to be whole and growing."*

When battling Alzheimer's disease, both the person with the disease and the partner experience loss. Mr. Unwin suggests finding replacements for the losses associated with Alzheimer's with new activities and new pleasures. "Human beings need to be whole and growing," he says. He and his wife started

collecting CDs, everyone from Duke Ellington to Alicia Keys to Charlotte Church. They watched herons on the San Jacinto River, and drove through the car wash on a regular basis. "That's how we staved our losses. We didn't go bankrupt. And nor should any man or woman who suffers loss," he says. "Filling up is the universal therapy – it's what makes you happy and whole."

#### **Editor's Note:**

These husbands changed their thinking about their wives' behavior and needs and thus improved the quality of their lives as couples. They used skills acquired at work and from years of experience. We know there are other success stories waiting to be told. Please send us yours.



**ANOTHER LOOK AT SUPPORT GROUPS**

By Garland Knott, Durham, NC  
May, 2004

In a recent issue of *The Caregiver* one writer expressed a strong dislike for support groups. Certainly he has a right to this opinion, because each person has different needs. However, my own experience has been entirely different.

Kathleen was always the strong person during our long marriage. She was a marvelous mother, and once the children were old enough, she held a very responsible job for more than twenty years. She was deeply religious, very widely read, and a fan of both sports and classical music. As a wife, she was both a great friend and a great lover.

When we moved to a Durham retirement home in 1999, she had been suffering from Alzheimer's for several years. She remained in our apartment for two years before transferring to the nursing home part of our continuing care community for the last six months of her life. It was my turn to be strong for her, and I needed all the help I could get!

As soon as we came to Durham, we began attending a support group sponsored by the Joseph and Kathleen Bryan Alzheimer's Disease Research Center. Perhaps our group is unique, but it has been a great source of strength to me and to others. Some members have been attending for more than ten years.

We meet at 10:30 a.m. once a month and adjourn at noon, when most of us go together to a nearby restaurant for lunch. Some members come from as far as 40 miles away.

The person with dementia and family members attend. Our leaders are three social workers. For the first half-hour, we have introductions, announcements, and any statements about significant recent experiences. At that point, two of the social workers retire with the dementia group to a nearby room, where they have their own discussions, often sharing stories or composing new stories as a group.

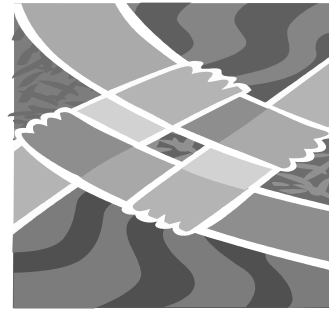
The family members and the third social worker then have freedom to express themselves during the remaining hour. We share information, problems, suggestions, experiences and empathy. Often we share laughter and tears. It is difficult to describe the depth of feeling that develops in our group, but I think that it is not amiss to call it love based on common concerns. Sometimes the heavy responsibility of caregiving is discussed, but never once have I heard an expression of bitterness or complaint.

Twice a year, in May and December, we have an informal meeting at the lovely home of one of our social workers. There we enjoy a delicious potluck meal, light conversation, and sometimes music provided by a talented member of our group. It is a chance to relax in an atmosphere of mutual understanding and care.

More than two years after Kathleen's death at age 76, I still attend the support group for two reasons. First, it helps me. Kathleen was one of ten children, six of whom have been afflicted with this dreadful disease. I want to be kept aware of all research developments, for the sake of our children and grandchildren. Besides, I enjoy being with friends in the group. Second, I hope to help someone else. New members are constantly joining the group, and perhaps they can benefit from the advice of the old hands. At least three members who have lost spouses continue to come; others have loved ones still at home, in day programs, or in nursing homes.

Here, then, is a support group that for many years has served the needs of persons struggling with the medical, social, financial, emotional and just plain physical aspects of dealing with dementia. I, for one, am profoundly grateful.

If you live anywhere near Durham, NC and you would like to know more about this group, call Roberta Wallace, Bryan ADRC at (919) 668-2836.



**Love**  
**The first duty of love is to listen.**  
**Paul Tillich**



## **AB** ACCESS to BENEFITS COALITION

### **New Access to Benefits Coalition Will Help Find Prescription Drug Savings for Lower-Income Medicare Beneficiaries**

More than 70 organizations, including the Alzheimer's Association, formally launched the Access to Benefits Coalition (ABC), a unique public-private partnership formed to reach out to, educate, and enroll Medicare beneficiaries with lower incomes in Medicare's new prescription drug savings program.

ABC's website, [www.accesstobenefits.org](http://www.accesstobenefits.org), includes unique state-specific Prescription Drug Savings Guides that provide an overview of federal and state government and pharmaceutical company savings programs available to residents. It also offers an Enrollment Center that contains forms, many of them fillable online, not offered anywhere else. The ABC site also offers a powerful Web-based decision support tool, BenefitsCheckupRx™. In a few minutes online, those who use it can determine which prescription savings programs they qualify for, including the Medicare-approved discount card program.



## WHAT CANNOT BE REPLACED

By George Glover  
Hickory, NC

I would like to introduce Mr. Alzheimer's. He is a thief that comes in uninvited and takes something that cannot be replaced. He moves into the brain slowly but surely and is there until death. Mr. Alzheimer's has taken away the young lady I met in high school. She waited for me to return from war to marry me fifty-eight years ago.

### The Good Old Days

This story begins when Esther was working in an office, driving, housekeeping, cooking and banking. She has been doing this for fifty odd years. We had a perfect marriage. Both of us loved to travel and camp with our son. Esther's job was getting on her nerves. I thought a vacation would help her. We made a six-week trip to California as a graduation present for our son. Esther started having heart trouble. We both retired. The next summer we drove to Alaska. This was a great trip with no problems (eleven weeks and eleven thousand miles). The next summer, friends made plans to go down the Natchez Trace Parkway and wanted us to travel with them. These were the last long trips we made.

### It Starts

One Sunday morning, she woke up sick. The vomiting was so bad, I decided to take her to the ER. After about an hour, she came out in the waiting room with wet pants. I asked what had happened. She said she had wet her pants. She told the nurse she needed to go, and the nurse went after a bedpan and never returned. I learned a valuable lesson from this experience. When taking someone to the ER, stay with them.

One day we were leaving the doctor's office (where we had been dozens of times). She said, "I am glad you are driving, because I don't know where we are." At this point, I decided to stop her from driving. Her license ran out. One day we were going by the patrol station. As a joke, I asked if she wanted to stop and get her license. She went in, passed the test and received a new license. Her giving up driving was hard on me. Now I had to do the driving she had been doing.

### Denial

As a caregiver, I know the meaning of denial. At the beginning it only seems like "a bad hair day." Esther and I visited people with the illness, but visiting for a few hours does not prepare a caregiver. Here is where an Alzheimer's support group can make life much easier.

### Adaptations

She wanted to go with me to buy groceries. She started complaining about me walking too fast for her. This made her mad. She would stop and stand like a stubborn bull. I was as stubborn as she and would go off and leave her standing. After so long, she got tired and would let me go without her. This suited me because she was no help. One day I came in with some

bananas with a black streak in the center. She knew I bought them at her least favorite store. From then on she would not eat anything from that store. I would pick up a couple extra bags and switch the produce into another store bag. After so long, she forgot about the bad bananas. Now it does not matter to her which store the food comes from.

Esther still tried to do some housekeeping, washing and cooking. Each time she used the washing machine, she put in too much soap. One day while she was washing, I went down stairs to see what she was doing. Part of the basement floor looked as if it had snowed. She knew it was the washing machine and not her. She demanded that I buy a new washer. To make her happy, I bought a new machine. She read the instruction book from cover to cover. This did not help, because she forgot the instructions before she finished reading. To this day, she has never washed with this machine. We later learned that the sewer pipe was full of roots, the source of the problem.

### **The Medical Merry-Go-Round**

Now I realized she had to have help. I told the doctor about her reaction and he wanted her to go to a mental health clinic. A nurse at this clinic thought she should see a psychiatrist at the hospital. After many questions, which Esther knew most of the answers, he thought she was depressed. They agreed to try Prozac. The doctor also wanted her to start going to a program for people with mental disorders. She attended two weeks. The patients were from rest homes and some were bad off, much worse than Esther.

### **Progression**

Esther always did the cooking and was a good cook. Baking was her hobby. I noticed she was having trouble reading and picking out the ingredients. Her memory would not hold a word long enough to pick out items she needed.

I received a notice from my cousin planning an 80th birthday dinner for her sister at a state park. The trip to the park was great. Of all the years we had camped, this was the first time she ever wanted to go home. This was the straw that broke the camel's back. I put the motor home up for sale. After forty enjoyable years camping, it was hard to give up.

I noticed she would get excited over nothing. We received a notice from the IRS stating the estimated tax was not paid. I paid the bill with an extra charge for being late. We received a notice from the county tax office saying the county taxes were not paid. She knew she had paid them but could not come up with a canceled check. I paid the bill with an extra charge for being late. One afternoon she decided to balance the check book with the statement. About ten P.M., I decided to go to bed. After getting ready, she told me I was not going to bed until the check book balanced. She came in, turned on the light and demanded I come help her. About three a.m., I decided to put her in the bed. She cried, prayed and cursed me. She then began begging for mercy. When I looked at the bank book, it looked like a child had been keeping the record. I had to start doing the banking. This hurt her more than the loss of driving privileges. She had kept the books and paid the bills ever since we were married. Instead of writing a check for each bill at the first of the month (as she had always done), I set up an account for all the bills to be drafted. She complained about me not paying the bills. This would hurt our credit.

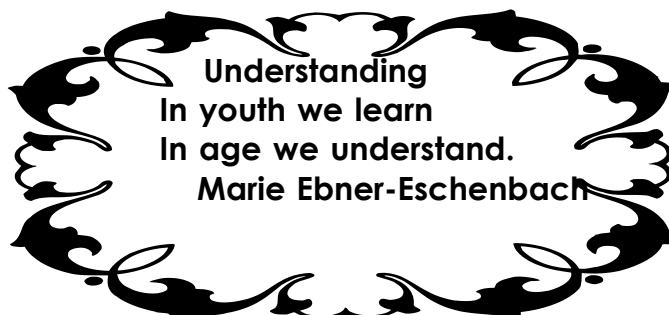
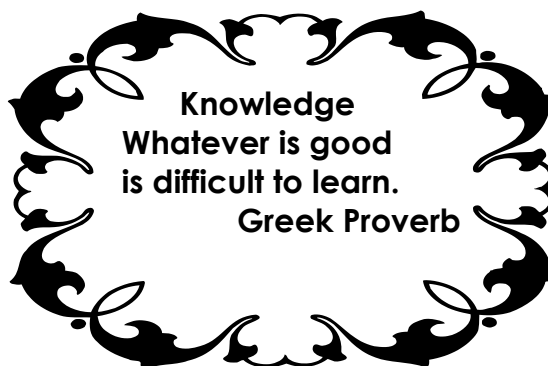
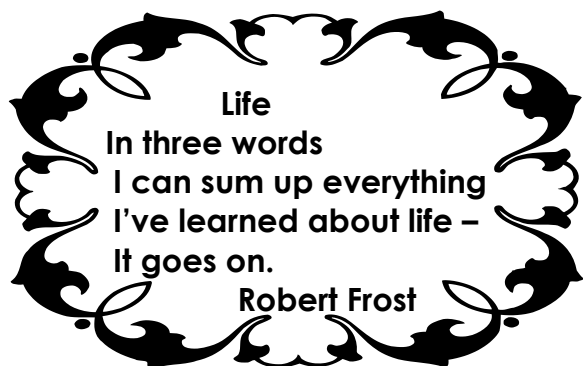
### The Worst of Times

I could not do anything right for her anymore and anything I did was wrong or against her. She began complaining about everything. If she saw or heard me talking to our son, we were plotting against her. As this got worse, my nerves were getting to the point I could not sleep. She would get upset about something after the evening meal. Losing sleep did not bother her.

Her doctor wanted her to see another doctor. We kept the appointment. The next day she had an appointment with her regular doctor. We told him about the new medicine she was on. He got upset and told her not to take any more of it. We never went back to that doctor.

One night she had something on her mind (I forget what) and could not get it to work out. A few minutes after getting in bed, the power went off. She asks why I turned the power off in her room. I heard her flipping switches. She screamed and I heard her hit the floor. As I was getting out of bed, the power came back on. When I walked in her room, she was sitting on the floor at the foot of her bed. Blood was on her hands and hair. Blood was coming out almost in a stream. I tried to get her to go to the ER, but she would not go. We wrapped a towel around her head and she went back to bed. When I went in her room in the morning, the place on her head was still bleeding. We went to the doctor. They found a small blood vessel was cut. She told everyone that would listen, if I had not turned the power off in her room, this would not have happened. Then she came up with the idea the bump on her head was the reason for her memory problem.

**Editors Note:** Mr. Glover is writing a book while caring for his wife. We will publish more chronological excerpts in the Spring 2005 issue of *The Caregiver*.





**Mother Came Back Today**

By Henry Walker, June, 2004 – Durham, NC

Mother came back today  
in reaction and even in words  
as Devon, Caitlin, and Morgan Jean  
hovered at her bedside  
and flew in on wings of love  
to kiss her and hug her  
and twinkle together with flashing eyes,  
two five-year-olds and a seven,  
one named for her,  
and Mother crowding in on 94,



Mother's glow brightening more each moment  
away from slumber and dreaming,  
the effort to get out of the gravity well of Alzheimer's  
just plain takes a lot of energy  
and if too few reactions are there when she ventures forth  
to connect with the program of words she can still access,  
why not retreat?

this afternoon smiles and tears and words release  
along with a joy from little ones  
so there for her and for themselves  
and there's what she gave us  
within the seeming randomness of so much of what she said:

"How sweet that is . . . thank you, darling. . .  
bless your little heart. . .thank you very much . . ."

[later]

"Listen. . .it was such a wonderful, wonderful, wonderful day. . ."

[and a tear flowed from her eye]

[later, as the kids didn't want to leave]

"My goodness, look at all those children. . .

There is my little one. . ."

[a kiss from Morgan Jean]

"Thank you, darling. . .today, today, today. . .

I think about the babies coming and they want to see them. . .

You can really see the weather. . .flowers. . ."

[then to Devon]

"You worked to be here, didn't you?"

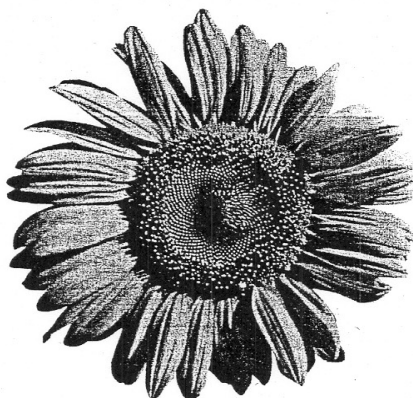
[and after Caitlin had hugged her]

"Oh, yes, we want you to see it lots of times. . .

I just want to think of my children. . ."

Mother can still be so much here  
because of who she has been and who she still is  
and because of the resources we can give to her care  
and the angels who give it,

and I feel for the countless others  
who can be lost within their own souls  
and within the misguided priorities of our self-indulgent politics.



# Zen Alzheimer's

BY SYLVIA HILL

Image Courtesy of Balkanfolk

One day about twelve years ago, my mother and I were standing in the condiments aisle in Harris Teeter. "Did you get the mayonnaise?" she asked. I pointed to the jar of low-fat mayo in our shopping cart. Satisfied, she wandered off to find another item. In about a minute, she was back. "Did you get the mayonnaise?" After another foray into the canned goods, she returned. "Did you get the mayonnaise?" I stared down the long colorful condiment aisle. Jars of mustard, ketchup and pickled relish bore silent witness to my sudden, stark realization: My mother had Alzheimer's disease.

The following twelve years have brought the inevitable trials and tribulations familiar to all caregivers. There was the traumatic move to the retirement home, the bouts of paranoid delusions, the cancer surgery, the first time she forgot my birthday, the first time she forgot me. As my mother lost her faculties, I felt like I was losing myself. Or at least the future self I had planned. The self, who would go back to school and change careers, would travel and perhaps work in Europe. What is it they say? Life is what happens while you make other plans.

Of course this is an old story, one that is familiar to the women in the caregiver support group I started attending when I got tired of facing everything alone. I see in their faces emotions shared by all caregivers: guilt, anxiety, frustration, worry, confusion and sometimes, anger. "I can't stand the poop and the piss anymore," says one woman, in tears. "I can't take it when my mother wishes she were dead," says another. "I have to just turn around and leave." "How can I stop my father from driving?" wonders a daughter. "Listening to

this makes me so sad," confides a newcomer. But then sometimes, the tide turns. Some comment or episode will be funny, or even profound.

One memorable story came from a soft-spoken widow who lost her mother to Alzheimer's disease. It was the middle of winter, and the cold, dead landscape mirrored the way she felt inside. As she looked out onto her patio, she saw them: bright, beautiful, fresh sunflowers, just lying there. Where had they come from? She suggested, how seriously I am not sure, that they were from her deceased husband. The boldness of her suggestion and the obvious, dramatic nature of the symbolism in those flowers have remained with me. Who am I to say? Maybe they were from her husband. "He's getting cheap," she said, smiling slightly. "He used to bring me roses!"

As I look around the table at these women, I realize our society thinks of us as "natural caregivers." I am proud to be a caregiver, but it is something I *do*, not who I *am*. Our labors in this arena are seen as "nonproductive," and consequently, there are serious repercussions for us socially, economically and professionally. The prevailing bottom line mentality devalues activities that do not generate income, a prime example being the long-term care of patients like my mother. Those who care for her, primarily women, hardly make a living wage. Family members like myself, who have had to delay career pursuits until middle age, find little help. As I come back to school and try to make a new start in the workplace, I find very few career-oriented degree programs that are practical for those of us not well endowed with youth and money. As one Duke professor recently observed, the Duke Women's

Initiative "does not acknowledge that women grow older." Neither, it seems, does feminism or our society in general. This needs to change, but where do we start? Examining the depth and breadth of ageism, and how this intersects with sexism, is a good place to begin.

In spite of all the difficult and sad situations I have experienced because of my mother's illness, I also have been periodically presented with my own bouquet of sunflowers. There was the time my mother took a new Alzheimer's drug and suddenly recognized me again. Amazingly, it seems to have stopped her mental decline in its tracks. Still, her world is one in which time has collapsed, one in which I am sometimes her sister, and where my grandmother (who would be 130) is still alive. As Mother deteriorated mentally I transferred her to an expensive facility, which had programs for patients with dementia. To keep her there, I spent everything she had, and unfortunately everything I had as well. Eventually, the money ran out.

Now she lives in a facility without that beneficial structured environment, so I need to find ways to engage and stimulate her mentally when I visit. We tried watching TV, but when the news came on, she thought the war in Israel was just across the street. I realized that my mother felt connected personally to everything she saw. Maybe a nature program would be good. We watched a show about whales. As we saw their huge bodies lumbering through the ocean on the small screen, she turned to me and asked, "What will I do if they come into my room?" They can't, I explained, because we are on dry land and they are in the ocean. "Are you sure?" She remained unconvinced. Perhaps television was not a good idea after all. Maybe a Sunday drive would do the trick.

We now have a regular ritual of going for a drive and then getting ice cream. "Let's go for a ride," I suggest, after putting away her clean clothes. "I'm going for a ride," she explains to fellow residents. "It's been nice knowing you," she says to the aide by the door, as if she will never return. "I love you!" Our drives are accompanied by her running commentary on our surroundings. "Oh, this is so beautiful," she says, looking at the countryside. "I love this country. Look at all those trees! We should get out and take a walk in those woods sometime. This country is so beautiful. It just shines up at us!" We come to an intersection and stop. "Isn't that a nice looking car?" she asks, pointing to the car in the next lane. "Isn't that pretty, that color red over there? That's so beautiful." At first I don't know what she means, but then realize she is talking about the stoplight. It occurs to me that

she is right. That *is* a nice car. The red color of the stoplight *is* beautiful. I didn't even notice. What *do* I notice?

The finale of our trip is a stop at Baskin Robbins. I bring out the strawberry ice cream and park in a spot that has a panoramic view. "This looks ridiculously good," she exclaims. She eats with relish, dripping ice cream on her blouse. "I'm really chomping on this, it's so good! The last bite is just as good as the first." She scrapes the cup with her spoon to get the last bit. Suddenly, she burps loudly. "Oh!" she comments without embarrassment. "That's the loudest one I've ever done!" We both laugh. Practicing my own feeble attempts at awareness, I point out the crows cawing on the lamppost. "Bless their hearts!" she says. "I feel kin to them. I feel like they are my relations!" I point out the sun starting to set. "It's going down so fast," she says, "we don't even have time to say goodbye. Farewell! Farewell!" After this dramatic goodbye to the sun, she tells me urgently that she would like to live here. "We do live here," I explain. "Oh," she replies, "I'm going to have to try and remember that."

I don't know why my mother suddenly developed this kinship with and awareness of the world around her. Perhaps it is some form of grace; an awareness gained in place of memories lost. I feel as if I am sitting with a Zen teacher who hits me on the head with a stick and says, "Wake up!" When was the last time I really noticed things? I remember as a child running out the door to play in a world that seemed to satiate the senses with a new sight or experience around every corner: a weird bug under a rock, tadpoles in the pond, or a game of kick ball. What happened?

What, indeed! I seem to spend each moment thinking about some other moment, trying to figure out what to do next, instead of noticing the surrounding world "shining up at me." My mother has been forced into the present because she cannot remember the past or comprehend a future. For me, being fully present in the moment must be a conscious choice. Isn't that where the poets and mystics are trying to lure us into the here and now?

But like many other caregivers, I seem to always be on the run: to work, to a medical appointment, to class, to visit my mother, to do the laundry, to buy her Depends, to clean my apartment. I can't stop doing these things, but my mother reminds me to wake up and engage the world, whether I am eating strawberry ice cream or emptying the potty chair. If I learn this lesson, it will be the hardest thing I have ever done. Perhaps the most profound lessons come in the least expected times and places, like a fresh sunflower lying on the porch in the dead of winter.



## Have You Heard About?

American Cancer Society's Guide to Pain Control: Understanding and Managing Cancer Pain (2004), product code #9637.00. \$18.95.

Burns, S and Fergie, R (2003). How to Care for Your Parents' Money While Caring for Your Parents. McGraw-Hill, New York, NY ; 294 pages.

Greenblat, CS (2004). Alive with Alzheimer's. Chicago: The University of Chicago Press. Pictorial essay hardback about a unique residential care setting for people with dementia. ISBN 0-226-30658-5.

Journeyworks Publishing (2004). Six one-page, low-literacy caregiver guides: 1) 50 Things Every Caregiver Should know; 2) Checklist for new caregivers; 3) Long-distance caregiving; 4) Caregiving: How to get the whole family involved; 5) Balancing caregiving, family and work; 6) When your loved one resists care. For preview: [www.journeyworks.com](http://www.journeyworks.com). (800) 775-1998. Quantity discount orders.

Kemp, BJ and Mosqueda, L (2004). Aging with a Disability: What the clinician needs to know. Johns Hopkins University Press. ISBN# 0-8018-7817-9, \$24.95 paperback; ISBN#0-8018-7816-0, \$55.00 hardcover.

Levine, C and Murray, TH (eds.) (2004). The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals and Policy Makers. Baltimore, MD. The Johns Hopkins University Press. [www.press.jhu.edu](http://www.press.jhu.edu). Hardback.

Miller, J (2004). The Savvy Senior: The Ultimate Guide to Health, Family and Finances for Senior Citizens. \$13.95. Paperback. New York, NY: Hyperion.

Mittelman, MS and Epstein, C. (2004). The Alzheimer's Health Care Handbook. Essential information for anyone involved in the care of a family member with Alzheimer's disease. Marlowe & Company. ISBN 1-56924-445-6. \$14.95.

Sifton, CB (2004). Navigating the Alzheimer's Journey: A Compass for Caregiving. Baltimore: Health Professions Press. Paperback. ISBN 1-932529-04-7.

The Merck Manual of Health and Aging. (2004). \$29.95 hardback for consumers. Whitehouse Station, NJ: Merck & Co. Inc.

Zien, L (2004). Tracking Your Medicine: How To Keep it Simple and Safe. (A daughter-in-law-caregiver's experience.). [www.boomerview.com](http://www.boomerview.com) or [www.amazon.com](http://www.amazon.com).



NATIONAL CENTER FOR COMPLEMENTARY AND ALTERNATIVE MEDICINE

## **10 THINGS TO KNOW ABOUT EVALUATING MEDICAL RESOURCES ON THE WEB**

### **1. Who runs this site?**

Any good health-related Web site should make it easy for you to learn who is responsible for the site and its information.

### **1. Who pays for the site?**

Web addresses ending in “.gov” denote a Federal Government-sponsored site. Does it sell advertising? Is it sponsored by a drug company? The source of funding can affect what content is presented, how the content is presented, and what the site owners want to accomplish on the site.

### **2. What is the purpose of the site?**

The purpose of the site should be clearly stated and should help you evaluate the trustworthiness of the information.

### **3. Where does the information come from?**

The original source should be clearly labeled.

### **4. What is the basis of the information?**

The site should describe the evidence that the material is based on. Medical facts and figures should have references (such as to articles in medical journals).

### **6. How is the information selected?**

Do people with excellent professional and scientific qualifications review the material?

### **7. How current is the information?**

It is important that medical information be current. The most recent update or review date should be clearly posted.

### **8. How does the site choose links to other sites?**

Some medical sites take a conservative approach and don't link to any other sites.

### **9. What information about you does the site collect, and why?**

Be certain that you read and understand any privacy policy or similar language on the site, and don't sign up for anything that you are not sure you fully understand.

### **10. How does the site manage interactions with visitors?**

There should always be a way for you to contact the site owner. If the site hosts chat rooms or other online discussion areas, are they moderated? It is always a good idea to spend time reading the discussion without joining in.



## Websites



[www.ahrq.gov/clinic/epcsums/demphsum.htm](http://www.ahrq.gov/clinic/epcsums/demphsum.htm). Summary of Evidence Report: Pharmacological Treatment of Dementia. 2004. Agency for Healthcare Research on Quality.

[www.cdc.gov/nccdphp/dnpa/physical/growing\\_stronger/index.htm](http://www.cdc.gov/nccdphp/dnpa/physical/growing_stronger/index.htm). Strength training for older adults.

[www.cdc.gov/nccdphp/dnpa/physical/pdf/lifestyles.pdf](http://www.cdc.gov/nccdphp/dnpa/physical/pdf/lifestyles.pdf). 2 page scientific evidence for promoting active lifestyle.

[www.aoa.gov/youcan](http://www.aoa.gov/youcan). Activity modification program for older adults.

[www.wiser.heinz.org/wiserrpt\\_life\\_rev\\_feb04.pdf](http://www.wiser.heinz.org/wiserrpt_life_rev_feb04.pdf). Seven life-defining financial decisions for women. Free 64 pp pdf file.

[www.fullcirclecare.org/caregiverissues/legal/legal.htm#guardian](http://www.fullcirclecare.org/caregiverissues/legal/legal.htm#guardian). New clear materials on guardianship.

[www.fullcirclecare.org/caregiverissues/general/safety.htm#hazards](http://www.fullcirclecare.org/caregiverissues/general/safety.htm#hazards). See *Falls & Fall Prevention*, 9 pp, 2004 booklet with excellent illustrations and checklists.

[www.fullcirclecare.org/caregiverissues/general/safety.htm#virtual](http://www.fullcirclecare.org/caregiverissues/general/safety.htm#virtual). Virtual house tool offers recommendations for safety and comfort of person living at home with AD and other chronic diseases.

[www.fullcirclecare.org/caregiverissues/general/safety.htm#hazards](http://www.fullcirclecare.org/caregiverissues/general/safety.htm#hazards). National Resource Center on Supportive Housing and Home Modification.

[www.fullcirclecare.org/caregiverissues/general/payhomemod.htm](http://www.fullcirclecare.org/caregiverissues/general/payhomemod.htm). Paying for home modifications and/or repairs.

[www.caregiveremployer.net/](http://www.caregiveremployer.net/). Excellent resource for employer and employee caregivers.

[www.fda.gov/cder/consumerinfo/Active12panel.pdf](http://www.fda.gov/cder/consumerinfo/Active12panel.pdf). 7 page booklet on medications.

<http://www.fda.gov/womens/pubs.html>. FDA fact sheets.

[www.HealingChronicPain.org](http://www.HealingChronicPain.org). Integrative Pain Medicine website.

[www.namenda.com](http://www.namenda.com). Information on the clinical benefits of Namenda from the pharmaceutical company.

[www.4woman.gov](http://www.4woman.gov). US Department of Health and Human Services. Women's Health Center.

[www.fda.gov/womens](http://www.fda.gov/womens). Food and Drug Administration. Women's Health Center.

[www.nih.gov/PHTindex.htm](http://www.nih.gov/PHTindex.htm). National Institutes of Health.

[www.ahrq.gov](http://www.ahrq.gov). Agency for Healthcare Research and Quality.

[www.lewybodydementia.org](http://www.lewybodydementia.org). New site for dementia with Lewy Bodies (DLB).

[www.alz.org](http://www.alz.org). Alzheimer's Association

[www.alzheimers.org/unravel.html](http://www.alzheimers.org/unravel.html). Alzheimer's Disease: Unraveling the Mystery. Provides basic information about AD and research.

[www.pfizerhelpfulanswers.com](http://www.pfizerhelpfulanswers.com). Find out how to get Pfizer medicines for free or at discount prices. Toll free 1-866-776-3700.

[www.canceradvocacy.org](http://www.canceradvocacy.org). Free cancer survival toolbox for people diagnosed with cancer.

[www.alzforum.org](http://www.alzforum.org). Information site containing news articles, discussion forums, interviews, research advances, directories etc.

[www.alzheimers.org](http://www.alzheimers.org). ADEAR site for information on AD research, diagnosis, treatment, drugs and clinical trials and Federal Government programs and resources.

[www.nlm.nih.gov/medlineplus/alzheimersdisease.html](http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html). An all-in-one search site for AD.

[www.pueblo.gsa.gov/cic\\_text/health/alzheim/brain.gif](http://www.pueblo.gsa.gov/cic_text/health/alzheim/brain.gif). Illustrates degenerative neurons in the brain and the areas responsible for motor, vision, sensory, speech and memory functions.

[www.webofcare.com](http://www.webofcare.com). How-to caregiving skills. To find the animations, follow the links "Alzheimer's/Dementia", and "Caregiving Skills."

[www.mayoclinic.com/home?id=3.1.2](http://www.mayoclinic.com/home?id=3.1.2). This Mayo Clinic site contains articles on driving, caregiving tips, nutrition, communication, stress management, depression, interactive caregiver stress tools and free email update service.

[www.alzheimers.org/pubs/longterm.html](http://www.alzheimers.org/pubs/longterm.html). Explores the options for long term care, with articles on planning ahead, making the right choice, and making a smooth transition.

[www.rush.edu/patients/radc/pdfs](http://www.rush.edu/patients/radc/pdfs). This manual contains 30 chapters on stages, treatment, communication, intimacy and more. Viewers can download the manual in pdf for free.

[www.biostat.wustl.edu/alzheimer](http://www.biostat.wustl.edu/alzheimer). Links aging and dementia sites and contains the AD discussion groups.

<http://clinicaltrials.gov>. Lists current trials and research. Provides information on name of the study, the purpose and eligibility information.

[www.merck.com/pubs/mm\\_geriatrics](http://www.merck.com/pubs/mm_geriatrics). Find descriptions and treatment information on conditions prevalent in the elderly.

[http://dietary-supplements.info.nih.gov/Health\\_Information/IBIDS.aspx](http://dietary-supplements.info.nih.gov/Health_Information/IBIDS.aspx). International database on dietary supplements.

Vision  
The question is not  
what you look at  
but what you see  
- Henry David Thoreau -

Intensity  
Out of intense complexities  
intense simplicities emerge  
- Winston Churchill -

Belief  
He is able who thinks he is able  
- Buddha -

Duke Family Support Program  
Duke University Medical Center  
Box 3600  
Durham, North Carolina 27710  
Phone: 919-660-7510  
(In NC 800-672-4213)  
[www.dukefamilysupport.org](http://www.dukefamilysupport.org)

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